

Mindfulness for people with long-term conditions and their family caregivers: a systematic review

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Title Page

Title:

Mindfulness for people with long-term conditions and their family caregivers: a systematic review.

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Abstract

Background and purpose: People with long-term conditions and their family caregivers can experience psychological difficulties. Mindfulness improves psychological wellbeing, but people with long-term conditions and their family caregivers rarely learn mindfulness together. This review systematically reviewed the therapeutic effects for people with long-term conditions and their family caregivers learning MBIs together in a partnership. The review asked what changes in psychological wellbeing or interpersonal factors do people with long-term conditions and their family caregivers experience when learning MBI together?

Methods: CINAHL, Medline, Nursing and Allied Health Database, PsycARTICLES, Psychology Database, PsycINFO were searched (1980-2017). Data were extracted and quality appraisal completed.

Results: The search identified 4008 studies, which reduced to 9 after screening. The review included varied designs: qualitative (n=2), quantitative (n=6), and mixed methods (n=1). Different conditions and various forms of partnerships were included. Mindfulness can alleviate psychological symptoms. Learning mindfulness in a partnership might improve dyadic coping and/or engagement with mindfulness. Results were sometimes contradictory and questions remain about the value of delivering mindfulness in a partnership.

Conclusions: Learning mindfulness in a partnership can improve psychological wellbeing, but improvements are often small and not experienced by everyone. Learning in a partnership can improve engagement with mindfulness and improve dyadic coping, but these findings are inconclusive and need further exploration.

Keywords:

Mindfulness; long-term conditions; psychological wellbeing; caregivers; partnership; systematic review.

1. Introduction

Long-term conditions (LTCs) such as depression, cancer, and cardiovascular disease are often seen in clinical practice and pose a significant health challenge worldwide [1]. The global nature of LTCs has resulted in them being a leading cause of poor health, mortality, and health expenditure within the United States [2] and Europe [3,4]. The scale of the challenge posed by LTCs is highlighted by figures from a large cross-sectional study in Scotland, which suggests 42.2% of participants (n= 1 751 841) had one or more LTC and 23.2% had two or more LTCs [3]. Similarly, figures from a Danish study revealed 29% of participants (n=162 283) reported having one LTC and 33% had two or more LTCs [4]. These figures suggest many people with LTCs have two or more conditions, with co-morbid psychological issues being common [5,6].

The prevalence and complex nature of multi-morbidity, including co-morbid psychological difficulties, creates pressure within health care systems and requires innovative solutions to improve outcomes for patients [7]. A key strategy to improve health outcomes for people living with LTCs or multi-morbidity is to use self-management (e.g. healthy lifestyle) and community-based interventions (e.g. Community Nurse) instead of hospital-based approaches [8]. A recent systematic review investigated the effects of people with an LTC involving family caregivers in the self-care of the condition [9]. This review discovered family involvement reduced hospital readmission rates, accident and emergency attendance, and anxiety levels. So combining family involvement and self-help strategies appears to reduce reliance on hospital-based services and therefore might also improve psychological wellbeing for people with LTCs [9].

Using family involvement to help support self-management of LTCs requires family caregivers to become more involved in the care and treatment of the person with the LTC. A family caregiver is defined as “any unpaid individual such as family member, friend and neighbour who provides care... [they]... can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately” [10]. Family caregivers are often spouses or adult children who may provide 30 plus hours care per week [11]. The challenges faced by family caregivers include interpersonal problems, difficulties supporting the family, and concern about wellbeing of the person with the LTC [12,13]. These challenges mean family caregivers often experience psychological distress themselves [14,15]. Thus, people with LTCs and their family caregivers frequently experience psychological consequences, although, interventions aimed at reducing this distress have tended to respond to them as individuals, ignoring the interconnected nature of these partnerships [16]. A growing body of research demonstrates the emotional and psychological interdependence between people living with LTCs and their family caregivers [17-19], so it is important to consider how people with LTCs and family caregivers can be supported together [20].

2. Background

Mindfulness-based interventions (MBIs) are now common within health care settings and people are aware of the potential benefits of mindfulness within clinical practice [21]. MBIs usually involve attending eight weekly group sessions, learning meditation practices (e.g. mindful breathing, body scan, and sitting meditation), and establishing a daily home practice of mindfulness [21]. MBIs help people develop present moment awareness and are thought to help alleviate health related difficulties [21]. The different components within MBIs make it difficult to know what the active ingredient is, although, evidence suggests the use of home practice [22] and increased mindfulness [23] are associated with better clinical outcomes. Two common mindfulness courses used in health care settings are mindfulness-based stress reduction (MBSR) [24] and mindfulness-based cognitive therapy (MBCT) [25]. The MBSR [24] and MBCT [25] courses are used in clinical settings and have the strongest evidence-base for effectiveness [26].

A systematic review and meta-analysis of systematic reviews has helped determined the effectiveness of MBSR [24] and MBCT [25] for different patient groups [26]. The analysis undertaken in the review included findings from 115 randomised controlled trials and included 8683 participants. This comprehensive systematic review revealed significant improvements in depression ($d=0.37$; 95%CI 0.28 to 0.45), anxiety ($d=0.49$; 95%CI 0.37 to 0.61), stress ($d=0.51$; 95%CI 0.36 to 0.67), quality of life ($d=0.39$; 95%CI 0.08 to 0.70), and physical functioning ($d=0.27$; 95%CI 0.12 to 0.42) for people with LTC following MBI [26]. Similarly, MBIs can help family caregivers experience reduced stress [27-29], improved depressive symptoms, decreased caregiver burden, and better quality of life [30]. Much of the existing research has focused on people with LTCs and family caregivers attending MBIs separately [31], with little attention given to the effect of people attending in patient-family caregiver partnerships.

3. Aim

This review systematically reviewed the therapeutic effects for people with LTCs and their family caregivers learning MBIs together in a partnership. The review asked what changes in psychological wellbeing or interpersonal factors do people with LTC and their family caregivers experience when learning MBI together in a partnership.

4. Methods

4.1. Design

A mixed methods systematic review protocol was registered with PROSPERO (International prospective register of systematic reviews) [32]. All study designs and research using mindfulness-based stress reduction [21,24], mindfulness-based cognitive therapy [25], or related mindfulness-based interventions were included in the review. Studies where mindfulness forms part of a broader approach were excluded from the review. The primary outcomes examined during the review were perceived stress, anxiety, and depressive symptoms. Secondary outcomes examined during the review included possible interpersonal changes within the partnership.

Table 1

Electronic Search of CINAHL (EBSCO).

S1	AB mindful*
S2	(MH "mindfulness")
S3	AB MBSR
S4	AB MBCT
S5	AB Breath*
S6	AB Meditat*
S7	(MH "meditation")
S8	AB Relax*
S9	(MH 'relaxation')
S10	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9
S11	AB Dyad*
S12	AB couple*
S13	(MH "couples' therapy")
S14	AB spous*
S15	(MH "spouses")
S16	AB Partner*
S17	AB Famil*
S18	(MH "Family Therapy")
S19	AB carer*
S20	AB Caregiver*
S21	(MH "Caregivers")
S22	S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21
S23	S10 AND S22 [limiters: published since 1980; English language; all adults].

4.2. Search methods

A search was completed in 2017 using keywords, subject headings, Boolean operators, and limiters [Table 1]. Databases used were AMED (EBSCOhost); The Cochrane Central Register of Controlled Trials (CENTRAL); CINAHL (EBSCOhost); Medline (EBSCOhost); Nursing and Allied Health Database (ProQuest); PsycARTICLES (ProQuest); Psychology Database (ProQuest); PsycINFO (ProQuest). Relevant websites and the reference lists of included papers were searched for suitable research to include in the review. One reviewer screened titles/abstracts using inclusion and exclusion criteria [Table 2] and coded them: 'include', 'undecided' or 'exclude'. All coded 'exclude' were removed, whilst those coded 'undecided' or 'include' were read as full text documents by two reviewers.

Table 2

SPIO (study design; participants; intervention; outcome) [33].

	Inclusion	Exclusion
Study design	Quantitative, qualitative, or mixed methods	Discussion papers or editorials
Participants	Adults with long-term conditions and their family caregiver	Under 18s

Intervention	MBI delivered to people with a long-term condition and a family caregiver together in a partnership	MBI delivered via telephone or virtually. Intervention where mindfulness is just one component of a broader intervention (e.g. Acceptance and Commitment Therapy and Yoga) Healthy people/couples attending MBI to improve parenting or romantic relationships
Outcomes	<ul style="list-style-type: none"> • Stress, anxiety, or depression • Psychological wellbeing • Interpersonal changes within the partnership 	

4.3. Quality appraisal

All studies were quality appraised using the Mixed Methods Appraisal Tool (MMAT) [34]. The MMAT includes two screening questions and up to 19 further questions depending on the research design. Quality appraisal was not used to exclude low quality studies from the review.

4.4. Data extraction

A data collection tool was developed and piloted. Data items related to the SPIO framework [33] and broad subject headings: 'changes to stress, anxiety and depression' and 'interpersonal changes in the partnership'. All data were extracted using the tool and uncertainties were discussed within the research team. Missing data was requested from authors and/or recorded as 'not reported' (NR). One author [35] provided anonymous data, which allowed for participants not attending in a partnership to be removed from the published findings. The mean, standard deviation, and *p*-value for the anonymous data were obtained using a Wilcoxon signed-rank test and Statistical Package for Social Science (SPSS version 22).

4.5. Synthesis of results

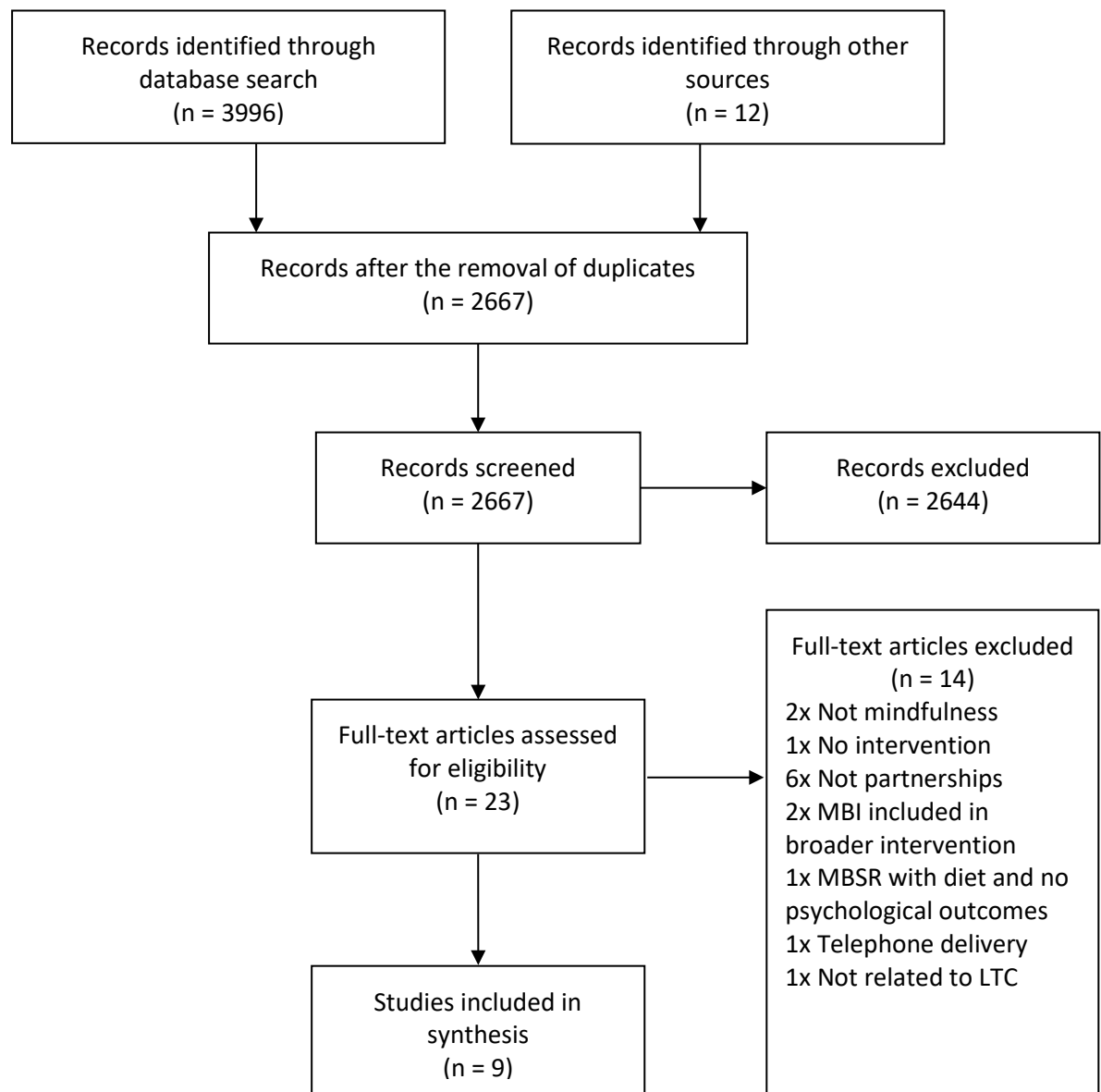
Results are presented as a narrative summary [36,37]. This process involved tabulating the results, describing the findings, and the provision of a narrative summary [36]. Different perspectives/methods were given equal weighting and synthesised to create conceptual triangulation within the narrative summary [37].

5. Results

5.1. Search outcome

The search yielded 4008 bibliographic records, which was reduced to 2667 after the removal of duplicates. The screening process identified 9 studies for inclusion in the review [Figure 1].

Figure 1
PRISMA [39].



5.2. Study characteristics

Six quantitative [35,40-44] and two qualitative studies [45,46], and one mixed methods [47] study was identified. Five quantitative studies were small-scale and used non-comparison pre/post-test designs [35,40-43]. One quantitative study [44] used a multicentre randomised controlled trial design, which compared MBI against 'care as usual' and incorporated a three-month follow-up period. Both qualitative papers [45,46] employed Grounded Theory methodology. The mixed methods study combined a single group pre/post-test design with semi-structured interviews and a three-month follow-up [47]. Five studies [35,40-43] were based in North America and four studies [44-47] came from Europe. The included studies in the review recruited people with a variety of LTCs: cancer [40,43,44,47]; Parkinson's disease [41]; multiple sclerosis (MS) [42]; amyotrophic lateral sclerosis (ALS) [45]; cognitive decline [35]; and recurrent depression [46] [Table 3].

Table 3
Study characteristics.

Study	Sample (Dyads)	Nature of Partnership	Diagnosis	Design	Intervention	Comparison	Data Collection
[35]	37 (14)	Mixed	Cognitive decline	Pre/post-test	MBSR	None	Beck Anxiety Inventory (BAI) Geriatric Depression Scale (GDS)
[40]	82 (41)	Couples	Cancer	Pre/post-test	MBSR	None	The Profile of Mood States (POMS) Calgary Symptoms of Stress Inventory (C-SOSI)
[41]	52 (NR)	Caregivers	Parkinson's	Pre/post-test	MBSR	None	Patient Health Questionnaire (PHQ9) Generalised Anxiety Disorder 7-Item (GAD7)
[42]	50 (25)	Married or living together	MS	Pre/post-test	MBSR	None	State-Trait Anxiety Index (STAI) Beck Anxiety Inventory (BAI) Dyadic Adjustment Scale (DAS)
[43]	52 (26)	Primary caregiver	Cancer	Pre/post-test	MBSR-C	None	The Perceived Stress Scale (PSS) Centre for Epidemiological Studies Depression Scale (CES-D scale) State-Trait Anxiety Inventory (STAI)
[44]	107 (41)	Partner	Cancer	Multicentre RCT with 3 month follow-up	MBSR	'Care as usual'	Hospital Anxiety and Depression Scale (HADS) Investment Model Scale- Satisfaction Sub Scale (IMS) Five Facet Mindfulness Questionnaire (FFMQ)
[45]	44 (18)	Caregiver	ALS	Qualitative evaluation/Grounded Theory	MBSR	None	Semi-structured interviews
[46]	16 (5)	Intimate-partner	History of depression	Grounded Theory	MBCT	N/A	Semi-structured interviews
[47]	35 (NR)	Partner	Cancer	Mixed method pilot study using pre/post-test design with 3 month follow-up	MBSR	None	Hospital Anxiety and Depression Scale (HADS) Penn State Worry Questionnaire (PSWQ) Mindful Attention and Awareness Scale (MAAS) Semi-structured interviews
Key: ALS= Amyotrophic lateral sclerosis MBCT= Mindfulness Based Cognitive Therapy MBSR= Mindfulness Based Stress Reduction MBSR-C= Mindfulness Base Stress Reduction for Cancer MS= Multiple sclerosis N/A= Not applicable NR= Not reported							

5.3. Participant characteristics

The total number of participants included 260 people with LTCs and 215 family caregivers, with an estimated 202 patient-family caregiver partnerships. The partnerships were couples/intimate partnerships [40,42,46,47], patient-caregiver partnerships [41,43,45], and a mixed group of partnerships [35,44]. Five studies [35,41,44,45,47] recruited individuals not in a partnership, so these studies combined individuals and partnerships within the same study. The age of participants varied between a mean age range of 48.5 [42] years and 72 [35] years for people with LTCs and 48.5 [42] years and 65.6 [41] years for family caregivers [Table 4].

Table 4
Participant characteristics.

Study	Total Participants	Patients	Patients Age: mean & (SD)	Patients Gender %	Patient diagnosis	Partners	Partner Age: mean & (SD)	Partner Gender %	Number of dyads	Nature of Dyad
[35]	37	17	72 (SD=NR)	Male: 70.59% Female: 29.41	Cognitive decline	20	62.5 (SD=NR)	Male: 20% Female: 80%	14	Mixed
[40]	82	41	62.9 (SD=7.37)	Male: 47.6% Female: 52.4%	Cancer	41	62.8 (SD=9.34)	Male: 52.4% Female: 47.6%	41	Couples
[41]	52	34	65.64** (SD=7.62)	Male: 53.8%** Female: 46.2%**	Parkinson's	18	65.64** (SD=7.62)	Male: 53.8%** Female: 46.2%**	NR	Patient-caregiver
[42]	50	25	48.53** (SD=NR)	Male: 40%** Female: 60%**	MS	25	48.53** (SD=NR)	Male: 40%** Female: 60%**	25	Couples
[43]	52	26	53.5 (SD=10.4)	Male: 30.8% Female: 69.2%	Cancer	26	51 (SD=14.6)	Male: 38.5% Female: 61.5%	26	Patient-caregiver
[44]	107	63	60.6 [§] /57.0 ^{\$\$} (SD=6.8) [§] /(SD=8.5) ^{\$\$}	Male: 42% [§] /53% ^{\$\$} Female: 58% [§] /47% ^{\$\$}	Cancer	44	60.8 [§] /56.6 ^{\$\$} (SD=8.2) [§] /(SD=10.4) ^{\$\$}	Male: 43% [§] /53% ^{\$\$} Female: 57% [§] /47% ^{\$\$}	41	Partners
[45]	44	26	61.9 (SD=NR)	NR	ALS	18	57.8 (SD=NR)	NR	18	Patient-caregiver
[46]	16	9	58 (SD=NR)	Male: 42.56% Female: 57.14%	Recurrent depression	7	58 (SD=NR)	Male: 40% Female: 60%	5	Couples
[47]	35	19	61.7 (SD=NR)	Male: 52.63% Female: 47.37%	Cancer	16	60.9 (SD=NR)	Male: 43.75% Female: 56.25%	NR	Couples
Key: *= Statistically significant $p < 0.05$ **= Data reported relates to whole sample \$= Treatment Group \$\$= Comparison group ALS= Amyotrophic lateral sclerosis MS= Multiple sclerosis NR= Not reported SD= Standard deviation										

5.4. Intervention characteristics

Seven studies [35,40-42,44,45,47] used MBSR [21,24], one study [43] used a modified MBSR for people with cancer, and one study [46] used MBCT [25]. All nine studies used group sessions with patients and family caregivers attending together. Eight studies [35,40-42,44-47] involved eight weekly face-to-face sessions. One study [43] delivered the course over six sessions using three face-to-face sessions and three audiotaped sessions. The use of home practice varied considerably between studies. Seven studies [35,40-44,47] provided guidance to participants about the recommended amount of home practice (e.g. 45 minutes most day), but participants sometimes practised much less (e.g. 20 minutes most days) [41]. Some studies encouraged and supported home practice using instructional manuals, [43,47], CDs [35,43,47], or home practice logs [35,41]. Two studies [45,46] in the review did not report whether home practice was encouraged or supported during their research. How well participants adhered to the MBI was evaluated by looking at completion rates within each study. Two studies [43,47] achieved completion rates in excess of 80% and one study [41] reported a completion rate of 75%. One study had completion rate of 50% [40], but the different thresholds used to determine completion makes comparisons difficult within this review.

6. Psychological wellbeing

6.1. Stress

Stress is a common feature for people living with LTC [5,6]. Stress was measured with the *Calgary Symptom of Stress Inventory* (C-SOSI) [48] and the *Perceived Stress Scale* (PSS) [49] [Table 5].

Table 5

Stress scores.

Study	Measure	Patient: pre/post test Mean (SD)		P value	Family caregiver: pre/post-test Mean (SD)		P value
[40]	C-SOSI	49.45 (35.40)	43.58 (2.10)	0.06	38.80 (29.27)	29.68 (16.19)	0.06
[43]	PSS	19.5 (7.1)	16.8 (6.0)	0.04*	18.1 (6.6)	17.1 (6.4)	0.29
Key: *= Statistically significant $p < 0.05$ C-SOSI= Calgary Symptoms of Stress Inventory PSS= Perceived Stress Scale SD= Standard deviation							

Patients and partners achieved an improvement in their mean stress scores in two studies [40,43], however, these result were only statistically significant ($p=0.04$) for patients in one study [43]. A third study [35] evaluated stress levels using a 5-point Likert scale and found patients and family caregivers experienced reduced stress (69%) and better coping (75%) following MBI.

6.2. Anxiety

Evaluating whether MBI had an effect on anxiety levels was an important aspect of this review. Anxiety was measured using the Generalized Anxiety Disorder-7 (GAD-7) scale [50]; the Penn State Worry Questionnaire (PSWQ)

[51]; the Hospital Anxiety and Depression Scale (HADS) [52]; the State-Trait Anxiety Inventory (STAI) [53]; and the Beck's Anxiety Inventory (BAI) [54]. Whilst not a tool specifically for anxiety, the Profile of Mood States (POMS) measure [55] includes a sub scale for tension/anxiety, which provides additional data on the potential benefit of MBI for anxiety [Table 6].

Table 6
Anxiety scores.

Study	Measure	Patient: pre/post test Mean (SD)		P value	Family caregiver: pre/post-test Mean (SD)		P value
[35]	BAI (Dyads only)	6.43 (7.94)	7.43 (13.63)	0.63	9.27 (9.37)	6.33 (5.84)	0.88
[40]	POMS Tension/ anxiety	5.57 (7.31)	3.05 (5.37)	0.01*/**	4.90 (6.49)	2.19 (3.95)	0.01*/**
[41]	GAD-7	6.23** (NR)	5.35** (NR)	0.292**	6.23** (NR)	5.35** (NR)	0.292** (NR)
[42]	BAI	NR	NR	NR	NR	NR	NR
	STAI	NR	NR	NR	NR	NR	NR
[43]	STAI: Trait	42.7 (12.6)	39.3 (10.2)	0.05*	38.5 (12.5)	37.8 (11.9)	0.61
	STAI: State	41.2 (13.3)	36.9 (13.6)	0.08	36.5 (13.4)	35.4 (14.8)	0.51
[47]	HADS (anxiety score)	7.1 (2.4)	6.2 (2.7) F/U 5.6 (3.8)	NR	10.6 (6.8)	9.4 (4.0) F/U 9.8 (4.0)	NR
	PSWQ	44.5 (15.0)	41.1 (12.3) F/U 38.8 (6.8)	NR	47.1 (10.0)	40.6 (17.2) F/U 43.3 (8.3)	NR
Key: *= Statistically significant $p=0.05$ **= Data reported relates to whole sample BAI= Beck's Anxiety Inventory F/U= Follow-up GAD-7= Generalised Anxiety Disorder 7-item HADS= Hospital Anxiety and Depression Scale NR= Not reported POMS= Profile of Mood States PSWQ= Penn State Worry Questionnaire STAI= State Trait Anxiety Inventory							

Significant ($p=0.01$) improvements in the tension/anxiety sub scale of the POMS measure [55] was reported in one study [40]. Another study [43] achieved significant ($p<0.05$) improvements in trait anxiety and non-significant improvement in state anxiety for patients with cancer, however, their family caregivers reported only marginal improvements. Similarly, some improvements were noted for patients' and their family caregivers' anxiety scores following MBI, but these changes were not significant at post treatment [35,41,47] or at follow-up [47]. Improvements to worry were recorded for people with cancer and their family caregivers using the PSWQ [51] at both

post MBI and at three-month follow-up [47]. One study [42] provided a narrative account of the BAI [54] results and reported no change in anxiety scores following MBI for participants with MS or family caregivers.

6.3. Depression

Depression symptoms can occur when living with a LTC [5,6], so investigating the effect of MBI on depression was an important aspect of this review. Depression was measured using the POMS measure [55]; the Patient Health Questionnaire (PHQ-9) [56]; the Centre for Epidemiological Studies Depressive Scale (CES-D) [57]; the Geriatric Depression Scale (GDS) [58]; and the HADS [52] [Table 7].

Table 7

Depression scores.

Study	Measure	Patient: pre/post test Mean (SD)		P value	Family caregivers: pre/post-test Mean (SD)		P value
[35]	GDS	8.00 (4.23)	7.00 (4.04)	0.18	8.44 (8.57)	6.50 (7.78)	0.018*
[40]	POMS	12.24 (31.03)	2.33 (23.42)	0.04*/**	6.71 (30.46)	2.76 (19.61)	0.04*/**
[41]	PHQ-9	6.36** (NR)	4.77** (NR)	0.011*/**	6.36** (NR)	4.77** (NR)	0.011*/**
[43]	CES-D	20.4 (11.7)	16.5 (11.4)	0.07	13.3 (9.1)	11.4 (9.3)	0.30
[47]	HADS (Depression)	6.2 (4.0)	6.5 (3.9) F/U 6.2 (4.3)	NR	8.1 (3.9)	6.3 (3.6) F/U 7.0 (5.0)	NR
Key: *= Statistically significant $p=0.05$ **= Data reported relates to whole sample CES-D= Centre for Epidemiologic Studies Depression Scale F/U= Follow-up GDS= Geriatric Depression Scale HADS= Hospital Anxiety and Depression Scale NR= Not reported PHQ-9= Patient Health Questionnaire POMS= Profile of Mood States							

Patients experienced a mean reduction in depression scores in four studies [35,40,41,43], whilst family caregivers experienced a mean reduction depression scores in five studies [35,40,41,43,47]. The improvements in depression were often small and only significant in three studies [35,40,41]. A significant reduction in depression scores was reported for cancer survivors ($p=0.04$) [40], people living with Parkinson's disease ($p=0.011$) [41], and some family caregivers [35,40]. Two studies in the review reported non-significant improvements in depressive symptoms for people living with LTC and family caregivers [43,47].

6.4. Psychological distress

General psychological distress can occur when people are affected by LTCs [5,13]. Psychological distress was measured using the combined anxiety and depression scores on the HADS [52]. Only one study [44] measured

psychological using the total anxiety and depression scores on the HADS [52]. The study [44] added MBI to 'care as usual' (CAU) and compared this combination with normal CAU at both post intervention and three-month follow-up.

Table 8
Psychological distress.

Patients								
Study	Measure	Baseline		Post-Treatment		3 Month Follow-Up		P Value
		MBSR Mean (SD)	CAU Mean (SD)	MBSR Mean (SD)	CAU Mean (SD)	MBSR Mean (SD)	CAU Mean (SD)	
[44]	HADS	11.97 (6.97)	12.94 (8.05)	10.03 (6.84)	13.10 (9.51)	8.29 (5.19)	13.89 (10.41)	0.008*
Partners								
[44]	HADS	13.81 (6.76)	14.74 (7.43)	13.88 (7.78)	13.42 (6.98)	12.73 (7.55)	11.69 (6.52)	0.661
Key: * Statistically significant $p < 0.05$ CAU= Care as usual HADS= Hospital Anxiety and Depression Scale MBSR= Mindfulness Base Stress Reduction SD= Standard deviation								

The study [44] achieved significant improvements ($p=0.008$) for patients receiving MBI at post treatment and 3-month follow-up. The significant improvements experienced by people living with LTC following MBI were not reported by family caregivers, who showed no significant change [44] during the study.

6.5. Qualitative findings

Three studies collected qualitative data [45-47]. The reported psychological benefits included increased relaxation, reduced worry, and reductions in anxiety [45-47], although, these potential benefits were not universal and some participants did report difficulty fully relaxing during the process [47]. Only one study [46] captured qualitative data on changes to depression and appeared to suggest a general improvement in mood. Triangulating the qualitative findings and the quantitative findings allows for a more comprehensive understanding of the issues and increases confidence in the results [59]. Triangulated qualitative and quantitative data suggests MBIs can improve relaxation, ease anxiety, and reduce depression for people with LTCs and their family caregivers. Improvements following MBI can be small and are not experienced by everyone.

7. Interpersonal factors within the partnership

The exploration of interpersonal factors within the partnership was an important element of the review. Within the review a variety of different approaches was taken to evaluate the impact of interpersonal factors for people with LTCs and their family caregivers attending an MBI together.

Studies focused on dyadic coping [42,46]; relationship satisfaction/quality [35,44,45]; whether attending in a partnership would improve engagement with mindfulness [41,44,46,47]; possible negative experiences [45,47]; and the development of a new theory to help understand the process of learning mindfulness in a partnership [46].

Dyadic coping was measured in one study [42] using the Dyadic Adjustment Scale (DAS) [60]. This analysis revealed a non-significant ($p=0.08$) improvement in dyadic coping for patients and family caregivers who meditated to the same extent. However, this improvement was not maintained when one member of the partnership meditated more, or less, than the other [42]. Another study [44] used the satisfaction subscale of the Investment Model Scale (IMS-S) [61] to evaluate whether MBI delivered to a patient-family caregiver partnership resulted in improved relationship satisfaction. Their analysis found no significant change in relationship satisfaction for either the patient ($p=0.806$) or family caregiver ($p=0.055$). Although, the high relationship satisfaction scores at baseline meant the scope for further improvement was limited and casts doubt on the usefulness of the results [44].

Table 9
Relationship satisfaction.

Patients								
Study	Measure	Baseline		Post-Treatment		3 Month Follow-Up		P Value
		MBSR Mean (SD)	CAU Mean (SD)	MBSR Mean (SD)	CAU Mean (SD)	MBSR Mean (SD)	CAU Mean (SD)	
[44]	IMS-S	6.84 (1.21)	6.42 (1.41)	6.82 (1.16)	6.51 (1.91)	6.86 (1.09)	6.35 (2.09)	0.806
Partners								
[44]	IMS-S	6.13 (1.29)	6.21 (1.18)	6.11 (1.31)	6.63 (1.32)	6.54 (1.05)	6.90 (1.00)	0.055
Key: CAU= Care as usual IMS-S= Investment Model Scale MBSR= Mindfulness Base Stress Reduction SD= Standard deviation								

One study [35] completed a post-treatment questionnaire using a 5-point Likert scale and found patients and partners (50%) felt their relationship had improved since starting the MBI. A different study [45] also noted a sub-theme of '*improvements in relationship*' in their qualitative analysis, whilst another study [47] found participants thought attending together would enable them to support each other using mindfulness. Conversely, a different study [41] considered whether patient and family caregivers attending together would influence session attendance, home practice or clinical outcomes. The outcomes of one study [41] found no relationship between attending in a partnership and attendance, home practice, or clinical outcomes. Similarly, one of the studies [44] discovered the effectiveness of MBIs were not moderated by attending in a partnership.

The potential benefit for people with recurrent depression attending MBI in a patient-family caregiver partnership was explored by one study [46]. The study [46] suggested attending in a patient-family caregiver partnership might facilitate session attendance, home practice, improve mutuality, and lead to participants taking increased responsibility for each other's wellbeing. This study [46] produced the Grounded Theory: 'learning new mindfulness skills together' [Figure 2], which suggests a reciprocal relationship between learning MBIs, partnership factors, and group processes. Therefore, attending MBI in a patient-family caregiver partnership might produce unique outcomes not experienced by those attending alone [46]. However, other studies [41,44] suggest attending in a partnership does not affect engagement or clinical outcomes, which creates contradictory findings about the effect of attending MBI in a patient-family caregiver partnership.

8. Quality appraisal within studies

The MMAT [34] appraisal tool was used to evaluate the quality of each study within the review. Quality appraisal highlighted weaknesses, but no studies were excluded from the review for having weaknesses. Common weaknesses within individual studies included lack of control groups [35,40-43,47], limited use of follow-up [35,40-43], and limited rigor within elements of the qualitative work [45,47].

9. Discussion

This systematic review explored the therapeutic effects for people with LTCs and their family caregivers learning MBIs together in a partnership. The review asked: what changes in psychological wellbeing, or interpersonal factors, do people with LTCs and their family caregivers experience when learning MBI together in a partnership? This review appears to be the first systematic review to explore MBIs from a partnership perspective and within the context of people with LTCs and their family caregivers. The review searched databases and other sources for primary research published between 1980-2017 and identified 9 studies meeting eligibility criteria. The studies all originate from North America [35,40-43] or Western Europe [44-47], so it appears research from other parts of the world is lacking or was overlooked by the search methods used in this review. The review took an inclusive approach to study selection, but the limited number of studies retrieved suggests this is an emerging area of investigation. Qualitative [45,44,47], quantitative [35,40,41,42,43], and mixed methods [47] studies were included, but often they did not include a comparison group [35,40-43,45-47] or collect follow-up data [35,40-43,45,46]. The included studies also used different research methods, which made comparison and synthesis of findings difficult. Variation existed in the studies in a variety of areas: the type of LTCs people were living with; the relationship between the people with a LTC and their family caregivers; whether people could attend the MBI without a partner; and the type of outcome measures used [Table 3]. The heterogeneity of the included studies makes it hard to determine whether socio-demographic factors (e.g. age, living arrangements etc.), relationship factors (e.g. type of relationship, quality of relationship etc.), or condition specific factors (e.g. type of LTC, severity etc.) have any impact of either the experience or outcomes associated with using MBI within a patient-family caregiver partnership. The review also identified methodological weaknesses during the quality appraisal process, which adds to the uncertainty about the results and findings within this review. The variation in research methods and methodological weaknesses discovered in this review make it difficult to reach any firm conclusions about the effect of people with LTCs and their family caregivers learning MBI together in a partnership.

9.1. Psychological wellbeing

MBIs appear to help improve psychological wellbeing by alleviating stress, anxiety, and low mood for some people. The potential for individual

improvement in psychological wellbeing following MBIs has been seen in previous reviews [62] and suggests a small effect size for depression (0.26) and a medium effect size for anxiety (0.47-0.24). Qualitative and quantitative findings from this review suggest a positive effect on psychological wellbeing for people with LTCs and their family caregivers following MBI. However, improvements were often small, not always statistically significant, and/or not experienced by everyone. Similarly, evidence from one of the studies [44] shows improvement in psychological wellbeing may only be experienced by patients and not their family caregivers. The variation in effect between each member of the partnership seen within this study [44] highlights the complex interconnections between people with LTC and their family caregivers [19,20]. The minimal improvement and variation in effect discovered in this review raises questions about the effectiveness of MBI for people living with LTCs and their family caregivers learning MBI together in partnership.

9.2. Interpersonal factors

Exploring the interpersonal factors for people with LTCs and their family caregivers learning MBI together in a partnership was an important and original feature of this review. The recently developed Grounded Theory: 'learning new mindfulness skills together' [46], suggests people with LTCs and their family caregivers might experience unique benefits when attending MBI together in a partnership. These benefits can include improved dyadic coping [42,46] and engagement with MBI [46]. Improved dyadic coping and engagement with MBIs has important clinical implications for people with LTCs and their family caregivers. Systematic reviews [63,65] have examined the clinical effects of dyadic coping and found improved dyadic coping can reduce the distress experienced by people living with a LTC. Equally, research examining the impact of engagement within MBIs found people who engage better with home practice achieve better outcomes [26,66]. The potential for people with LTCs and their family caregivers to experience improved dyadic coping [42,46] and/or better engagement [46] when learning MBI together in a partnership is important, but not all research evidence agrees on the subject. Contradictory evidence suggests attending MBIs in a partnership might not improve engagement [41] or clinical outcomes [41,44]. These conflicting findings on the subject of engagement [41] and clinical outcomes [41,44] make it difficult to ascertain if interpersonal and partnership factors have an effect on people with LTCs and their family caregiver learning MBI together in a partnership. To fully understand the effect of people with a LTC and their family caregivers learning MBI together in a partnership, it is necessary to explore the complexity of attending MBI in a patient-family caregiver partnership.

Delivering MBIs to people with LTCs and their family caregivers together in partnership has several interconnected components and is highly complex [68]. Differing views within the literature about the mechanism of change within MBIs [67], combined with the possibility some people benefit more from the interpersonal elements [46], means clarity is needed about how MBIs work within this context [64]. This uncertainty highlights the complexity within some healthcare interventions and the importance of deconstructing them into: whole interventions (e.g. MBSR), component parts (e.g. body scan or

group process etc.), and powers (e.g. active ingredient) [68]. This conceptualisation is complicated further by the dyadic context when people living with LTCs and their family caregivers learn MBIs together in a partnership. The therapeutic potential of MBIs for people with LTCs and their family caregivers might be linked to: individual factors, interconnections between the individuals within the partnership, specific components within the intervention, the differing powers associated with each of these elements or a combination of any of these factors. This multifaceted and complex picture needs to be explored further before the effects of MBI for people living with LTCs and family caregivers can be fully understood.

9.3. Strength and limitations of review

The study adopted an inclusive approach and incorporated qualitative, quantitative, and mixed methods designs. This review aligned with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidance [39]. The main weaknesses in the review relate to using English language and 'abstract only' limiters during the search, which risked missing important studies published in other languages and/or without an abstract. Similarly, the provision of a narrative summary could be seen as a weakness in this review. A narrative summary is acceptable for a mixed methods synthesis, but does lack transparency and is vulnerable to bias [37]. Finally, five of the included studies [35,41,44,45,47] had samples that consisted of individuals and people in a partnership. Combining individual and partnership findings together in the same study made it difficult to interpret the findings separately. The weaknesses identified within the review mean the findings should be interpreted cautiously.

9.4. Implication for practice

MBIs are increasingly used within clinical practice, but engagement and adherence can be poor. Usually MBIs involve people living with LTCs and their family caregivers learning separately, but learning MBI in patient-family caregiver partnership might offer additional benefits for participants. These benefits can include better engagement and/or improved dyadic coping, although, the findings are mixed and sometimes contradictory. Robust research is needed to fully explore the experience and outcomes associated with using MBI within patient-family caregiver partnerships. It would be useful to research the experience and outcomes associated with learning MBI within a patient-family caregiver partnership for people with different LTCs (e.g. stroke, diabetes etc.) and in different forms of partnerships (e.g. spouses, siblings etc.). It would also be useful to employ more robust research design (e.g. mixed methods, follow-up etc.) and to explore different methods for delivering MBIs to patient-family caregiver partnerships (e.g. online, virtually etc.). This work could help guide future implementation of MBIs for people living with LTCs and their family caregivers.

10. Conclusions

This mixed methods systematic review explored the effect for people with LTC and their family caregivers attending MBIs together in a partnership. People with LTCs and their family caregivers can experience improvements in

psychological wellbeing following MBI, but improvements are often small, not always significant, or experienced by everyone. Tentative findings suggest people with LTCs and their family caregivers can experience improved dyadic coping and/or increased engagement with MBIs when they learn together in a patient-family caregiver partnership. Delivering MBIs to people with LTCs and their family caregivers together can have effects on the psychological wellbeing and interpersonal elements within the partnership, but further research is needed to fully explore this method of delivery.

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